

# SHORT REPORT

## Palliative care for prenatally diagnosed lethal fetal abnormality

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Diagnosis of lethal fetal abnormality raises challenging decisions for parents and clinicians. Most parents opt for termination, which may include feticide. Advances in imaging seem unlikely to lead to earlier diagnoses. Perinatal palliative care offers an alternative. Parental decision making and the clinical aspects of perinatal palliative care were studied after a prenatal diagnosis of lethal fetal abnormality in 20 pregnancies. 40% of parents chose to continue the pregnancy and pursue perinatal palliative care. Six of these eight babies were liveborn and lived for between 1½ h and 3 weeks.

The management of pregnancies complicated by lethal fetal abnormality poses challenges for both obstetricians and paediatricians. Issues of access to termination of pregnancy and gestation limits are matters of professional, political and public debate. Some informed and lay opinion expects advances in prenatal diagnosis to exclude the need for late termination of pregnancy. Presently, termination is legal at any gestation when there is a substantial risk of severe mental or physical disability for the child.<sup>1</sup> After 22 weeks, this would usually involve feticide.

When parents decide to continue a pregnancy, health professionals may be unfamiliar with alternative management, such as perinatal palliative care.<sup>2</sup> This avoids the psychological effect of abortion on parents<sup>2,3</sup> and clinicians. We sought to determine decision making and pregnancy outcome where a lethal fetal abnormality was diagnosed after 18 weeks and where parents were offered the option of pregnancy termination or perinatal palliative care.

### METHODS

We followed up pregnancies in three categories of lethal abnormality diagnosed in the Division of Maternal-Fetal Medicine, Addenbrooke's Hospital, Cambridge, UK, from 2001 to 2005: trisomy (18 and 13), renal tract abnormality and major skeletal dysplasia. Parents were offered the option of termination of pregnancy or continuation with palliative care for the baby. All post-22-week abortions included a feticide procedure.<sup>3</sup>

Consultants in fetal medicine, neonatology, a midwife counsellor and sometimes other specialists, such as geneticists and surgeons participated in discussions with parents. The difficulty in predicting the timing and place of death was emphasised. Death could occur before, or within hours, days or weeks of birth, and could occur in the delivery unit or neonatal unit, or at home. Management options included non-intervention for suspected fetal compromise, with fetal death a possibility, and induction of labour at term.

The plans agreed on were clearly documented and circulated to all participating healthcare professionals. Parents had the option to alter their plans at any stage. A consultant neonatologist attended delivery to ensure consistent clinical practice and to support staff and parents.

We determined what proportion of women chose to pursue perinatal palliative care, the features of affected pregnancies and the period of perinatal palliative care. We studied time from initial referral to confirmed diagnosis, time to parental decision and the plan agreed for perinatal care. Autopsy and postnatal karyotyping were offered in all cases.

### RESULTS

In all, 20 lethal abnormalities in these categories were diagnosed in the study period, including 12 renal tract abnormalities, 3 skeletal dysplasias and 5 trisomies diagnosed after 18 weeks; 12 pregnancies were terminated and 8 (40%) were continued (2 with trisomy 18, 5 with renal tract abnormality and 1 with skeletal dysplasia).

The median (range) gestation of confirmed diagnosis was 20 (18–32) weeks; time taken from referral to specialist diagnosis of lethal anomaly was 1 (0–14) day and for parents to decide whether to terminate or continue after diagnosis was 1.5 (0–8) days. Median (range) maternal age in affected pregnancies was similar for both groups: in those continuing with the pregnancy, 29 (22–41) years; and in those requesting termination, 30 (18–37) years. Median (range) parity was 1 (0–2). One baby was delivered by emergency caesarean section for an abnormal fetal heart trace, despite a plan for palliative care, at the mother's request.

When palliative care was chosen, there were two stillbirths (5 weeks and 8 weeks after diagnosis) and six livebirths. Median (range) gestation at delivery was 36 (34–38) weeks. Babies survived for 1½ h to 3 weeks (median 1 day). In one case, postmortem karyotyping disclosed trisomy 18 in a severely growth-restricted stillborn fetus with renal anomalies. In three of the five remaining fetuses without trisomy, a postmortem examination was carried out, in all cases confirming prenatal diagnoses. Table 1 summarises outcomes in continuing pregnancies.

### DISCUSSION

Lethal fetal abnormalities are uncommon; we made only 20 such diagnoses in fetuses after 18 weeks' gestation in three defined categories over four years. For many, diagnosis in the first trimester is possible with combined ultrasound or biochemical screening and invasive testing; however, late diagnoses will continue to arise as incidental discoveries.<sup>3</sup> Furthermore, skeletal and renal abnormalities may require serial scans and second opinions before lethality can be established.

Most women request termination after a diagnosis of lethal abnormality. This was true for 60% in our cohort. Feticide is usually carried out for termination after 22 weeks.<sup>1,3</sup> This may be unpleasant for parents and clinicians, and some parents would rather continue the pregnancy. Without feticide, such a termination risks livebirth even in the context of diagnostic certainty regarding lethality,<sup>1</sup> with the attendant complications of birth registration, and even possible referral to the coroner.

**Table 1** Pregnancy and neonatal outcomes in continuing pregnancies

	Stillborn babies (n = 2)	Liveborn babies (n = 6)
Birth weight, g	1292 (985–1600)	1684 (1410–3129)
Gestation at birth, weeks*	36 (34–38)	38 (34–38)
Place of death, n	NA	Delivery unit, 3 Neonatal unit, 2 Community, 1
Final diagnosis, n	Trisomy 18, 2	Renal agenesis, 3 (1 with trisomy 18) Posterior urethral valves with pulmonary hypoplasia, 1 Hydrolethrus syndrome, 1 Bilateral renal dysplasia, AVSD (Goldenhar syndrome), 1
Age at death*	NA	1 day (1 h–21 days)
Features of palliative care, n	Planned delivery at regional centre, 2 Post mortem, 0 Postnatal counselling, 2	Planned delivery at regional centre, 5  Delivery at local district hospital, 1 Neonatal consultant at delivery, 5  Use of opiates, 3 Ventilated, 2 Transfer to community team, 1 Post mortem, 3 Postnatal counselling, 6

AVSD, atrioventricular septal defect; NA, not applicable.

\*Values are median (range).

**Table 2** Proposed framework for perinatal palliative care service

Action	Benefit
Multidisciplinary joint counselling by fetal medicine specialist, neonatologist and midwife counsellor (further specialists as indicated—eg, clinical geneticist)	Agree diagnosis and prognosis; clear and consistent communication; efficient use of time for both clinicians and patients—avoiding multiple appointments and travel
Clearly documented plan for delivery and perinatal period in maternal and prebirth notes and copy for parents and referring centre	Ensures all staff have access to key information at all times, avoiding repeated discussions with parents; parents carry documentation in case of unplanned delivery elsewhere
Liaison with community services supporting palliative care (GP, hospice, community paediatrics)	Ensures community child health team has advance plan if death after discharge home is a possibility
Liaison with hospital chaplaincy or representatives for other faith and religions	Parents' wishes for ceremonies at the time of baby's death may be discussed and arranged
Discussion of case at multidisciplinary meetings, ongoing discussion and liaison with referring centres	Provides forum for ongoing discussion of case; support for staff
Offer parents contact information for ARC and SANDS and if requested, further specialist second opinions	Ensures that parents have full information from sources independent of immediate healthcare team
Senior neonatologist attends delivery	Avoid inappropriate resuscitation decisions by junior staff; reassurance for parents and obstetric staff for senior neonatologists to confirm diagnosis and outlook
Interval postnatal follow-up with key obstetric, midwifery and neonatal staff	Gives parents a valuable chance for debriefing remote from the events, and feedback of postmortem examination and other investigations

ARC, antenatal results and choices; GP, general practitioners; SANDS, Stillbirth and Neonatal Death Society.

Advances in neonatal care and prenatal diagnosis are cited as reasons for reducing gestation limits for termination. New imaging modalities, such as three-dimensional or four-dimensional ultrasound, or fetal magnetic resonance imaging, would not facilitate earlier diagnosis in cases reported here. Interest in these imaging modalities is in our view a distraction to the debate on the gestation time at which termination is legal.

Restrictions to the upper gestation limit for termination of pregnancy would magnify the challenges for clinicians and parents, as a limit of 20 weeks would require detailed scans to be taken at 16–18 weeks, which is before a confident diagnosis of renal or skeletal abnormalities or chromosomal markers is apparent. Also, there are inherent delays from referral to specialist review (in our series, this was up to 14 days), and

from review to diagnosis and subsequent parental decision (of up to 8 days).

We report that 40% of couples made a positive decision not to terminate the pregnancy, preferring to pursue perinatal palliative care. This may avoid feelings of guilt,<sup>2</sup> and allow parents and other family members to spend time with, and prepare for, the baby's death. Here, an advance individualised plan of care should be agreed on by the parents and the obstetrics, midwifery and neonatal staff, aiming to optimise outcomes—including psychological ones—for the whole family. A framework for legal, clinical and ethical practice in circumstances where a poor prognosis is expected has been published by the Royal College of Paediatrics and Child Health.<sup>4</sup> Table 2 outlines the basic principles for perinatal palliative care and our findings.

Most babies with lethal abnormality were liveborn when the parents continued the pregnancy, in keeping with recent American experience.<sup>5</sup> Our series shows the variable and unpredictable postnatal course of these babies, ranging from immediate neonatal death to survival for several weeks.

Experience of practising palliative care for babies with lethal abnormalities is limited, in part owing to the difficult nature of these problems and their relative rarity. In our experience, those parents who chose this model of care gave positive feedback about their decision and the care provided. Professional organisations and specialist societies are best placed to develop how obstetricians, paediatricians and other health professionals can develop this practice. With dedicated resources, guidelines and training, and an agreed framework for practice, more parents could benefit from perinatal palliative care as an alternative to termination of pregnancy.

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